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ABSTRACT

The incorporation of human immune deficiency virus/acquired immune deficiency syndrome (HIV/AIDS) into identity over time was examined by collecting data from the same 11 HIV-positive individuals at 3 points in time (in 1995, early 1998, and late 1999). By the time of their semi-structured interviews in late 1999, the seven men and four women interviewed had been HIV-positive for between 7 and 16 years. An analysis of the nature of the learning reported by the study participants revealed the existence of a six-point incorporation process that included the following stages: (1) diagnosis (the beginning of incorporation of HIV/AIDS into identity and often included shock, fear, denial, and relief); (2) a post-diagnosis turning point (that was often referred to as a "catalytic experience" and involved social interaction; (3) immersion (during which participants actively participated in the HIV/AIDS community); (4) a post-immersion turning point (which caused a reevaluation of priorities); (5) integration (a stage that was marked by HIV/AIDS identity decentralization; and (6) a disclosure process (a process that progressed from disclosure to significant others only to public disclosures followed by situational disclosures on a need-to-know basis). This process of incorporation was transformational and also included increased appreciation for the human condition and an expanded view of intimacy. (Contains 12 references.) (MN)

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The Incorporation of HIV/AIDS into Identity over Time: Transformational Tales Continued

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Abstract: Using data collected from the same individuals at three points in time, this qualitative study explored the incorporation process of HIV/AIDS into identity. In addition, the nature of learning that occurred was investigated. A six-component incorporation process emerged. Transformative learning occurred and new meaning schemes were uncovered.

HIV/AIDS is considered a chronic illness in the U. S (Beaudin and Chambre, 1996). As Americans live longer with HIV/AIDS, they need to adjust their thinking on health care issues as well as core developmental issues such as the evolution of their identity. With HIV/AIDS now considered a chronic disease, and since identity development is a lifelong process, the study's focus was how people incorporate HIV/AIDS into their identity *over time*.

While studies investigated the impact of HIV/AIDS on various aspects of identity (Bedell, 1998), and the identity incorporation process (Gurevich, 1996; Lewis, 1994) none examined the incorporation process *at three points in time*. Since HIV/AIDS is a chronic illness and identity development is a lifelong process, it was believed that a study that examined the incorporation of HIV/AIDS at three points in time would contribute to a better understanding of the incorporation process.

Learning drives identity development. Our ability to reflect and have dialogue with ourselves and with others helps us learn and change (Mezirow, 1991). Thus, transformational learning is implicit in the incorporation of HIV/AIDS into identity. Yet, no study was found that directly addressed the nature of learning during the incorporation of HIV/AIDS into identity. An investigation of meaning-making over time could contribute to a more complete understanding of transformational learning.

Theoretical Framework

The narrative approach to identity development informs this study. This approach "looks at the storied nature of development and considers story a metaphor for human life" (Rossiter, 1999, p. 59). McAdams's (1988) life-story model to identity exemplifies this approach. Each life story is comprised of "nuclear episodes" or high points, low points, and turning points. Everyone also has a generativity script which he defines as "a vision of exactly what one hopes to put into life and what one hopes to get out life" (p. 27).

Mezirow's (1991) transformational learning theory informs this study. This theory asserts that learners critically examine their beliefs and

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assumptions through self-reflection and by talking with others and arrive at a broader, more inclusive worldview. The new perspective is irreversible. Further, Mezirow believes that people continue to adjust their meaning schemes and that development occurs in a positive direction.

Little empirical evidence for the stability of the perspective transformation exists. (Courtenay, Merriam, Reeves, and Baumgartner, 2000; Williams, 1986) This study aims to further understanding on the stability of the perspective transformation and the continued meaning-making of participants over time.

Methodology

This study was the *third* conducted with the same participants in four years. A qualitative research design was considered appropriate to understand the dynamic, evolving process of identity incorporation and the nature of learning that occurs during the process. Research questions included: (1) What are the components of the identity incorporation process? (2) What is the nature of learning that occurs during the incorporation process?

Data sets from two previous studies were utilized in addition to a third round of interviews conducted by the researcher. The initial 1995 study sought to understand meaning making "in the lives of HIV-positive men and women" (Courtenay, Merriam, and Reeves, 1998, p. 65). A follow-up study in early 1998 examined the stability of the perspective transformation experienced by participants (Courtney, Merriam, Reeves, and Baumgartner, 2000). The current study concentrated on identity incorporation issues. Data from the first two studies augmented information contained in the most recent interviews.

Data was collected through semi-structured interviews that were conducted in November and December of 1999. Eleven participants (7 men, 4 women) were interviewed. They had been HIV-positive between 7 and 16 years. Interview questions focused on identity incorporation issues and what changes had occurred in their meaning-making of their disease since last interviewed. Interviews were tape recorded and transcribed. Interviews were analyzed using three methods of narrative analysis: (1) Gee's (1990) sociolinguistic approach, (2) Denzin's (1989) and McAdams's (1988) biographic methods, and (3) Alexander's (1988) psychological approach. Comparisons within and between transcripts were made and common patterns emerged.

Findings

A six component process of incorporation of HIV/AIDS into identity was uncovered. *Diagnosis* was followed by a *post-diagnosis turning point*. During *immersion*, participants actively participated in the HIV/AIDS community. A *post-immersion turning point* caused a revaluation of priorities while *integration* was marked by HIV/AIDS identity decentralization. Last, a *disclosure* process was uncovered.

There were four major findings regarding the nature of learning during the process of incorporation: (1) The nature of learning was transformational and the perspective transformation remained stable over time; (2) Meaning scheme changes discovered in 1998 remained and participants had taken action on them; (3) There were additional meaning scheme changes (4) Social interaction was a prominent factor in the transformational learning process.

Diagnosis

The diagnosis was the beginning of incorporating HIV/AIDS into identity. Shock, fear, denial, and relief were common reactions to diagnosis. John was shocked. "My way of describing the world went upside down…I ended up driving the wrong way down the interstate…I was dazed." Elise expressed fear saying, " I was in a level of terror. Complete soul shock." Most participants also went through a period of denial that lasted from six months to five years (Courtenay, Merriam, and Reeves, 1998). Sam "turned to alcohol" while Kenneth "fed [his] addiction." Dawn

"put [HIV] in this little box." Jeffery, the only person to mention being relieved at the diagnosis, believed he was destined to get HIV. When he was diagnosed, no longer did "the dragon follow [him] around anymore."

Post-diagnosis turning point

Courtney, Merriam, and Reeves's (1998) study also recognized a post-diagnosis turning point called a "catalytic experience" (p. 71). Participants indicated that this turning point involved social interaction. All participants had a clear post-diagnosis turning point. Tracy noted, "I was thinking about how I was going to commit suicide…a guy started following me and I asked him to sit down and talk…. He was also HIV-positive…He gave me his card and eventually I made the decision to go to a support group." Steve stated, " I became good friends with a woman [who led] a course in miracles. I began to wake up to the thought that a miracle could happen…I had major reasons to connect with people."

Immersion

There were three components to the immersion process: (1) People became immersed in the HIV/AIDS community; (2) the HIV/AIDS identity was central, and (3) Participants educated others. Immersion in the community gave respondents a sense of belonging and empowerment. Pat's comments were typical: "It helped…just knowing I wasn't by myself…I started volunteering at AIDS organizations right off. It was a major factor in [identity incorporation]. I don't think I could have done it by myself." Dawn' words exemplified the centrality of the HIV/AIDS identity. She remembered when HIV/AIDS consumed her life. She stated, "I went to the far end of the spectrum…Everything was AIDS. I couldn't have a conversation that didn't include AIDS…. I had become this poster child. It was all-consuming." Finally, many were compelled to educate others. Sam said, "I got to the point where it was like-there's a lot of ignorance out there and I can do something about that."

Post-Immersion Turning Point

Participants spent several years in the immersion component of the incorporation process. Eventually, an event or series of events caused them to reexamine their involvement in the HIV/AIDS community and the centrality of their HIV/AIDS identity. For many, access to life-extending medications was that turning point. Steve noted, "Protease inhibitors came out…I think everyone breathed a sigh of relief and wanted to think, 'Ding-dong the witch is dead. THANK GOD.'" Sam wondered about his future, "Inhibitors came out and it was like 'Oh my God, I have to live now. How the hell am I going to live?" Others, such as Tracy, did not want to be known as "HIV/AIDS Tracy" and she got involved in other activities outside of HIV/AIDS.

Integration

This stage was marked by (1) time and health dependent decentralizing and, (2) balancing Respondents had lived with the disease and had time to integrate it. Jeffery stated, " I went from being in its shadow… to acceptance. The dragon doesn't tower over me anymore. It's kind of like the story of the three pigs. The wolf…finally came down the chimney and I cooked him and I ate him so he's part of me. Health concerns, however, bring the HIV/AIDS identity to the fore.
While decentralizing refers to the internal experience of the HIV/AIDS identity, balancing is the external manifestation of that change. People engaged in other activities. Sam "took a sabbatical from HIV/AIDS work to re-do a house." Tracy "went bowling."

Disclosure

Disclosure was the thread that wove itself through the process. First, people told only *significant others*, then made *public disclosures*, and finally made *situational disclosures* on a need-to-know basis. Each of the three types of disclosure corresponded with a component of the incorporation process. During diagnosis people informed significant others. Public disclosure corresponded with the immersion component

while situational disclosure occurred during integration. Initially, the stigma of the disease kept people from telling others. Dawn stated, " For a long time it was a huge secret. Half the family didn't know."

Public disclosure often first occurred in support groups. Later, people felt compelled to educate others and spoke publicly about their disease. Jamie's statement was typical, " Initially, I had to claim AIDS publicly to get help…Later, I went on the national news. All of a sudden I'm the spokesperson for all these people. It became a real identity at that point."

Situational disclosure occurred after more complete integration. Tracy said, "I thought I had to tell everyone. Now I don't have to tell everyone." Steve stated, " I had this real need to tell people before. Now…I don't introduce myself with it."

The Nature of Learning: Stability of the Perspective Transformation

The nature of learning was transformational. People continued to maintain their perspective transformation as evidenced by their continued need to make a meaningful contribution, heightened sensitivity to life, and need to be of service to others. All continued to be involved in HIV/AIDS service organizations and like Dawn, found that HIV "gave [her] a purpose." Pat reiterated, "This is my life's mission." Similarly, all continued to appreciate life and others. When interviewed in 1998, Kenneth said, " I can [always] find things to be grateful for." Kenneth summed up many participants sentiments in the 1999 interviews by stating, "It's a great day to be alive" while Dawn "spent an enormous amount of time celebrating that fact [she is] alive." Finally, all needed to continue to be of service to others through work in service organizations.

Stability of Meaning Scheme Changes

In 1998, Courtenay, Merriam, Reeves, and Baumgartner (2000) found new meaning scheme changes: (1) People had an increased orientation toward the future; (2) Participants strove for more balance in their lives, and (3) there was increased HIV/AIDS identity integration. These schemes held and were acted on. In 1998, Jamie's realization that he may live longer served as a turning point. By 1999, he was employed full-time and was planning for retirement. Jeffery anticipated remaining healthy. He said, "One of the most daring things that I did…was to buy a condominium on the second floor…which meant I had to climb stairs.

Participants continued to strive for balance. In 1998, Dawn realized her need for balance. By 1999, she was taking time off from her plethora of committees and commitments to hike the Appalachian Trail. She said, "The last thing you want is …to be…so obsessed with making a contribution that you don't take care of yourself…. So all of your effort to be good and kind…you have diminished your contribution." Joe began "eating right" and "taking care of [his] body" because he realized he was going to live longer.

Integration of HIV/AIDS into identity was increasingly evident. In 1998, Kenneth referred to HIV as "a pet" while Elise called it "my partner." By 1999, the virus was so integrated that it was not a separate entity. Kenneth stated, "[HIV]-it is just part of-what I do. It's just part of my life." Elise concurred, "It is something that is, but I don't really think about it." John stated, "It is a reality that is there, but so is my white skin. So is my gray hair."

Additional Meaning Scheme Changes

There were additional meaning scheme changes. People demonstrated; (1) an increased appreciation for the human condition and, (2) an expanded view of intimacy.

Increased appreciation for the human condition. People increasingly accepted their own and others' failings. Jeffery discussed forgiving others

when he stated, "I've reconnected with a friend who fired me [when he discovered that I had AIDS]…I understand where he was coming from…New beginnings can always happen. Kenneth simply said, "I'm more open-minded today. I'm more accepting of people." Pat shared that she used to feel superior to others with HIV/AIDS because of her healthier lifestyle. She admitted, "I used to [think] that I was better but I don't do that anymore. I have to allow them to be where they are."

Expanded view of intimacy. Time allowed people to reflect on their relationships with significant others. Kenneth, who in 1998, said he "had no problem with women" and that "most of my female friends are positive and are very much aware of that fact that I am" had a new view of his relationships in 1999. He had realized that intimacy was multi-layered. He explained, "There's a physical level, a mental level, and a spiritual level and I grew beyond just the physical experience….I desire more." Joe realized that improved health was allowing his "sexual [self] to wake back up again." He realized that he could never "go back to the casual sex place again" because his "period of non-sexuality has changed the way [he] deals with men" in that he's found he can be "very affectionate [without] having any sort of sexual relationship."

Social Interaction: The Influence of the Group

Mezirow (1991) alludes to the importance of social interaction in the transformational learning process. Social interaction with other HIV-positive people was integral to the incorporation process. Group membership helped destigmatize the disease. Dawn went to a weekend workshop at an AIDS Service Organization and found "real people living lives." This helped her realize that HIV/AIDS "was not only something that…social deviants deserve." Previous to joining a group Sam "felt like a pariah-unloved and unlovable." Interaction with other HIV-positive people transformed Joe who felt "isolated" into "an AIDS poster boy" who now lobbies the legislature of AIDS drug assistance money.

Conclusions and Implications

This study confirms that there is a general progression through phases of incorporation though the *rate* of progression is highly individualized. It also emphasizes the importance of transitions/turning points in the incorporation process. Third, this study suggests disclosure is integral to the incorporation process and indicates that situational disclosure may indicate a level of integration beyond that experienced by telling the public.

The nature of learning during the incorporation process is transformational. This study goes beyond previous investigations (Courtenay, Merriam, and Reeves, 1998; Courtenay, Merriam, Reeves, and Baumgartner, 2000). It confirms the stability of the perspective transformation and recognizes that previous meaning schemes remain stable *and are acted upon*. Meaning schemes continue to change. People are not asking the "big" questions about life assumptions (premise reflections), they are engaging in process reflection which looks at new ways to implement their world view (Courtenay, Merriam, Reeves, and Baumgartner, 2000).

Last, this study found social interaction integral to the learning process. This is not entirely surprising since Mezirow's (1991) concept of rational discourse involves examining the validity of new meaning schemes and perspectives. What *is* surprising is *how* important social interaction was to participants' learning process and how many needs were met through this interaction. In a sense, the HIV/AIDS support group was a "full service" station for the integration of the new perspective. People realized that they were not alone on this transformational journey, found a place where they could engage in rational discourse, try on new roles, and gain confidence within the group. Social interaction also filled affective needs.

Regarding the nature of learning during the process of incorporation, my study provides empirical support that the learning is transformational and the perspective transformation remains stable. Previous meaning schemes remain stable and are acted on. The stability of the perspective transformation should be both cause for celebration and caution among educators Challenging students' preconceived notions seems to be worth the effort. However, ethical issues arise. What right does the educator have to plan for the transformation? (Courtney, Merriam, Reeves, and Baumgartner, 2000).

Second, educators should be encouraged that meaning schemes continue to change. Courtenay, Merriam, Reeves, and Baumgartner (2000) note that since "fundamental beliefs and assumptions of learners are continuously changing…our efforts to configure learning experiences that help learners examine their meaning schemes may be productive" (p. 117). In addition, adult educators should note people act on these meaning scheme changes. They should be encouraged to assist learners to *act* on new meaning schemes.

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